

1 AMENDMENT TO HOUSE BILL 1102

2 AMENDMENT NO. _____. Amend House Bill 1102 by replacing
3 the title with the following:

4 "AN ACT in relation to aging."; and

5 by replacing everything after the enacting clause with the
6 following:

7 "Section 1. Short title. This Act may be cited as the
8 Family Caregiver Act.

9 Section 5. Legislative findings. The General Assembly
10 recognizes the following:

11 (1) Family caregivers, serving without
12 compensation, have been the mainstay of the long-term
13 care system in this country. Care provided by these
14 informal caregivers is the most crucial factor in
15 avoiding or postponing institutionalization of the
16 State's residents.

17 (2) Among non-institutionalized persons needing
18 assistance with personal care needs, two-thirds depend
19 solely on family and friends for assistance. Another 25%
20 supplement family care with services from paid providers.
21 Only a little more than 5% rely exclusively on paid

1 services.

2 (3) Family caregivers are frequently under
3 substantial physical, psychological, and financial
4 stress. Unrelieved by support services available to the
5 caregiver, this stress may lead to premature or
6 unnecessary institutionalization of the care recipient or
7 deterioration in the health condition and family
8 circumstances of the caregiver.

9 (4) Two out of 3 family caregivers, due to being
10 employed outside the home, experience additional stress.
11 Two-thirds of working caregivers report conflicts between
12 work and caregiving, requiring them to rearrange their
13 work schedules, work fewer than normal hours, or take an
14 unpaid leave of absence. For this population, caregiver
15 support services have the added benefit of allowing
16 family caregivers to remain active members of our State's
17 workforce.

18 Section 10. Legislative intent. It is the intent of the
19 General Assembly to establish a multi-faceted family
20 caregiver support program to assist unpaid family caregivers
21 and grandparents or other older individuals who are relative
22 caregivers, who are informal providers of in-home and
23 community care to older individuals or children.

24 Services provided under this program shall do the
25 following:

26 (1) Provide information, relief, and support to
27 family and other unpaid caregivers of older individuals
28 and children.

29 (2) Encourage family members to provide care for
30 their family members who are older individuals and
31 children.

32 (3) Provide temporary substitute support services
33 or living arrangements to allow a period of relief or

1 rest for caregivers.

2 (4) Be provided in the least restrictive setting
3 available consistent with the individually assessed needs
4 of older individuals and children.

5 (5) Include services appropriate to the needs of
6 family members caring for older individuals and children,
7 including older individuals with dementia.

8 (6) Provide family caregivers with services that
9 enable them to make informed decisions about current and
10 future care plans, solve day-to-day caregiving problems,
11 learn essential care giving skills, and locate services
12 that may strengthen their capacity to provide care.

13 Section 15. Definitions. In this Act:

14 "Caregiver" or "family caregiver" means an adult family
15 member or another individual, who is an informal provider of
16 in-home and community care to an older individual, or a
17 grandparent or older individual who is a relative caregiver.

18 "Child" or "children" means an individual or individuals
19 18 years of age or under.

20 "Department" means the Department on Aging.

21 "Eligible participant" means a family caregiver or a
22 grandparent or older individual who is a relative caregiver.

23 "Family caregiver support services" includes, but is not
24 limited to, the following:

25 (1) Information to caregivers about available
26 services.

27 (2) Assistance to caregivers in gaining access to
28 the services.

29 (3) Individual counseling, organization of support
30 groups, and caregiver training for caregivers to assist
31 the caregivers in making decisions and solving problems
32 relating to their caregiving roles.

33 (4) Respite care to enable caregivers to be

1 temporarily relieved from their caregiving
2 responsibilities.

3 (5) Supplemental services, on a limited basis, to
4 complement the care provided by the caregivers.

5 (6) Other services as identified by the Department
6 and defined by rule.

7 "Frail individual" means an older individual who is
8 determined to be functionally impaired because the individual
9 (i) is unable to perform from at least 2 activities of daily
10 living without substantial human assistance, including verbal
11 reminding, physical cueing, or supervision or (ii) due to a
12 cognitive or other mental impairment, requires substantial
13 supervision because the individual behaves in a manner that
14 poses a serious health or safety hazard to the individual or
15 to another individual.

16 "Grandparent or older individual who is a relative
17 caregiver" means a grandparent or step-grandparent of a
18 child, or a relative of a child by blood or marriage, who:

19 (1) lives with the child;

20 (2) is the primary caregiver for the child because
21 the child's biological or adoptive parents are unable or
22 unwilling to serve as the primary caregiver for the
23 child; and

24 (3) has a legal relationship to the child, such as
25 legal custody or guardianship, or is raising the child
26 informally.

27 "Informal provider" means an individual who is not
28 compensated for the care he or she provides.

29 "Older individual" means an individual who is 60 years of
30 age or older, except for a grandparent or older individual
31 who is a relative caregiver.

32 "Respite care" means substitute supports or living
33 arrangements provided on an intermittent, occasional basis.
34 The term includes, but is not limited to, in-home respite

1 care, adult day care, child care, and institutional care. The
2 term also includes respite care as defined in Section 2 of
3 the Respite Program Act to the extent that such services are
4 allowable and participants are eligible under the National
5 Family Caregiver Support Program.

6 Section 16. Family caregiver demonstration grant. The
7 Department shall seek federal funding for the establishment
8 and assessment of a Family Caregiver Training and Support
9 Demonstration Project. The Department is authorized to fund 2
10 sites, one in a rural community and one in a more urban area.
11 The Department shall adopt rules governing participation and
12 oversight of the program. The Department shall seek
13 technical assistance from the Department of Public Aid and
14 the Department of Human Services. The Department shall
15 advise the Governor and the General Assembly regarding the
16 effectiveness of the program within 6 months after the
17 conclusion of the demonstration period.

18 Section 20. Powers and duties of the Department. The
19 Department shall administer this Act and shall adopt rules
20 and standards the Department deems necessary for that
21 purpose. At a minimum, those rules and standards shall
22 address the following:

23 (1) Standards and mechanisms designed to ensure the
24 quality of services provided with assistance made
25 available under this Act.

26 (2) Data collection and record maintenance.

27 The Department shall administer this Act in coordination
28 with Section 4.02 and related provisions of the Illinois Act
29 on the Aging.

30 Section 25. Provision of services. The Department shall
31 contract with area agencies on aging and other appropriate

1 agencies to conduct family caregiver support services to the
2 extent of available State and federal funding. Services
3 provided under this Act must be provided according to the
4 requirements of federal law and rules, except for the
5 provision of services to grandparents or older individuals
6 who are relative caregivers when State funding is utilized to
7 provide those services.

8 Section 30. Eligibility for respite and supplemental
9 services. When a family caregiver is providing in-home and
10 community care to an older individual, the older individual
11 must be a frail individual as defined in this Act in order
12 for the family caregiver to be eligible to receive respite
13 and supplemental services.

14 Section 35. Health care practitioners and facilities not
15 impaired. Nothing in this Act shall impair the practice of
16 any licensed health care practitioner or licensed health care
17 facility.

18 Section 40. Entitlement not created; funding; waivers.

19 (a) Nothing in this Act creates or provides any
20 individual with an entitlement to services or benefits. It is
21 the General Assembly's intent that services under this Act
22 shall be made available only to the extent of the
23 availability and level of appropriations made by the General
24 Assembly.

25 (b) The Director may seek and obtain State and federal
26 funds that may be available to finance services under this
27 Act, and may also seek and obtain other non-State resources
28 for which the State may be eligible.

29 (c) The Department may seek appropriate waivers of
30 federal requirements from the U.S. Department of Health and
31 Human Services.

1 Section 90. The Respite Program Act is amended by
2 changing Sections 1.5, 2, 3, 4, 5, 6, 8, 11, and 12 as
3 follows:

4 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

5 Sec. 1.5. Purpose. It is hereby found and determined by
6 the General Assembly that respite care provides relief and
7 support to the primary care-giver of a frail ~~or-abused~~ or
8 ~~functionally disabled or-cognitively-impaired-elder~~ adult and
9 provides by-providing a break for the caregiver from the
10 continuous responsibilities of care-giving. Without this
11 support, the primary care-giver's ability to continue in his
12 or her role would be jeopardized; thereby increasing the risk
13 of institutionalization of the frail ~~or--abused~~ or
14 ~~functionally disabled or-cognitively-impaired-elder~~ adult.

15 By providing ~~improving-and-expanding-the-in-home~~ respite
16 care ~~services---currently--available~~ through intermittent
17 planned or emergency relief to the care-giver during the
18 regular week-day, evening, and weekend hours, both the
19 special physical and psychological needs of the primary
20 care-giver and the frail ~~or-abused~~ or ~~functionally disabled,~~
21 ~~or--cognitively-impaired-elder~~ adult, who is the recipient of
22 continuous care, shall be met reducing or preventing the need
23 for institutionalization.

24 Furthermore, the primary care-giver providing continuous
25 care is frequently under substantial financial stress.
26 Respite care and other supportive services sustain and
27 preserve the primary care-giver and family caregiving unit.
28 It is the intent of the General Assembly that this amendatory
29 Act ~~of-1992~~ ensure that Illinois primary care-givers of frail
30 ~~or--abused~~ or ~~functionally disabled or-cognitively-impaired~~
31 ~~elder~~ adults have access to affordable, appropriate in-home
32 respite care services.

33 (Source: P.A. 87-974.)

(320 ILCS 10/2) (from Ch. 23, par. 6202)

Sec. 2. Definitions. As used in this Act:

(1) "Respite care" means the provision of intermittent and temporary substitute care or supervision of frail or abused or functionally disabled or cognitively-impaired-older adults on behalf of and in the absence of the primary care-giver, for the purpose of providing relief from the stress or responsibilities concomitant with providing constant care, so as to enable the care-giver to continue the provision of care in the home. Respite care should be available to sustain the primary care-giver throughout the period of care-giving, which can vary from several months to a number of years. Respite care can be provided in the home, in a community--based day care setting during the day, overnight, in a substitute residential setting such as a long-term care facility required to be licensed under the Nursing Home Care Act or the Assisted Living and Shared Housing Act, or for more extended periods of time on a temporary basis.

(1.5) "In-home respite care" means care provided by an appropriately trained paid worker providing short-term intermittent care, supervision, or companionship to the frail or disabled adult in the home while relieving the care-giver, by permitting a short-term break from the care-giver's care-giving role. This support may contribute to the delay, reduction, and prevention of institutionalization by enabling the care-giver to continue in his or her care-giving role. In-home respite care should be flexible and available in a manner that is responsive to the needs of the care-giver. This may consist of evening respite care services that are available from 6:00 p.m. to 8:00 a.m. Monday through Friday and weekend respite care services from 6:00 p.m. Friday to 8:00 a.m. Monday.

(2) "Care-giver" shall mean the family member or other

1 natural person who normally provides the daily care or
 2 supervision of a frail, abused or disabled elderly adult.
 3 Such care-giver may, but need not, reside in the same
 4 household as the frail or disabled adult.

5 (3) (Blank). "Provider" shall mean any entity enumerated
 6 in paragraph (1) of this Section which is the supplier of
 7 services providing respite.

8 (4) (Blank). "Sponsor" shall mean the provider, public
 9 agency or community group approved by the Director which
 10 establishes a contractual relationship with the Department
 11 for the purposes of providing services to persons under this
 12 Act, and which is responsible for the recruitment of
 13 providers, the coordination and arrangement of provider
 14 services in a manner which meets client needs, the general
 15 supervision of the local program, and the submission of such
 16 information or reports as may be required by the Director.

17 (5) (Blank). "Director" shall mean the Director of
 18 Aging.

19 (6) "Department" shall mean the Department on Aging.

20 (7) (Blank). "Abused" shall have the same meaning
 21 ascribed to it in Section 103 of the Illinois Domestic
 22 Violence Act of 1986.

23 (8) "Frail or disabled adult" shall mean any person
 24 suffering from Alzheimer's disease who is 60 55 years of age
 25 or older and or any adult 60 years of age or older, who
 26 either (i) suffers from Alzheimer's disease or a related
 27 disorder or (ii) is unable to attend to his or her daily
 28 needs without the assistance or regular supervision of a
 29 care-giver due to mental or physical impairment and who is
 30 otherwise eligible for services on the basis of his or her
 31 level of impairment.

32 (9) "Emergency respite care" means the immediate
 33 placement of a trained, in-home respite care worker in the
 34 home during an emergency or unplanned event, or during a

1 temporary placement outside the home, to substitute for the
 2 primary care-giver. Emergency respite care may be provided
 3 in--the--home on one or more occasions unless an extension is
 4 deemed necessary by the case coordination unit. When there
 5 is an urgent need for emergency respite care, procedures to
 6 accommodate this need must be determined. An emergency is:

7 (a) An unplanned event that results in the
 8 immediate and unavoidable absence of the primary
 9 care-giver from the home in an excess of 4 hours at a
 10 time when no other qualified care-giver is available.

11 (b) An unplanned situation that prevents the
 12 primary care-giver from providing the care required by a
 13 frail or abused-or-functionally disabled or cognitively
 14 impaired adult living at home.

15 (c) An unplanned event that threatens the health
 16 and safety of the frail or disabled adult.

17 (d) An unplanned event that threatens the health
 18 and safety of the primary care-giver thereby placing the
 19 frail or abused-or-functionally disabled or cognitively
 20 impaired-elder adult in danger.

21 (10) (Blank). "Primary--care-giver"--means--the--spouse,
 22 relative,--or--friend, 18-years-of-age-or-older,--who-provides
 23 the-daily-in-home-care-and-supervision-of-a-frail--or--abused
 24 or-functionally-disabled-or-cognitively-impaired-elder-adult.
 25 A-primary-care-giver-may,--but--does--not--need--to,--reside--in--the
 26 same--household--as--the--frail--or--abused--or--functionally
 27 disabled--or--cognitively-impaired-adult.-A-primary-care-giver
 28 requires-intermittent--relief--from--his--or--her--caregiving
 29 duties-to-continue-to-function-as-the-primary-care-giver.

30 (Source: P.A. 91-357, eff. 7-29-99; 92-16, eff. 6-28-01.)

31 (320 ILCS 10/3) (from Ch. 23, par. 6203)

32 Sec. 3. Respite Program. The Director is hereby
 33 authorized to administer a program of establish--respite

1 projects-for-the-purposes-of-providing-care-and assistance to
2 persons in need and to deter the institutionalization of
3 frail or disabled or--functionally--disabled--or--cognitively
4 impaired adults.

5 (Source: P.A. 87-974.)

6 (320 ILCS 10/4) (from Ch. 23, par. 6204)

7 Sec. 4. No Limit to Care. Nothing contained in this Act
8 shall be construed so as to limit, modify or otherwise affect
9 the provisions, for long-term in-home services being provided
10 under of Section 4.02 of the Illinois Act on the Aging.

11 (Source: P.A. 87-974.)

12 (320 ILCS 10/5) (from Ch. 23, par. 6205)

13 Sec. 5. Eligibility. The Department may establish
14 eligibility standards for respite services taking into
15 consideration the unique economic and social needs of the
16 population for whom they are to be provided. The population
17 identified for the purposes of this Act includes persons
18 suffering from Alzheimer's disease or a related disorder and
19 persons who are 60 55 years of age or older, or persons age
20 60-and-older with an identified service need. Priority shall
21 be given in all cases to frail,--abused or functionally
22 disabled or cognitively-impaired adults.

23 (Source: P.A. 87-974.)

24 (320 ILCS 10/6) (from Ch. 23, par. 6206)

25 Sec. 6. Responsibilities. The--following-requirements
26 shall-apply-for-any-projects-authorized-under--Section--3--of
27 this-Act:

28 (a) The Department Director shall administer this Act
29 and shall adopt rules and standards the Department deems
30 necessary for that purpose establish-target-areas-needing
31 respite-care-services.

1 (b) The Department Director shall make grants to or
 2 contract with Area Agencies on Aging and other appropriate
 3 community-based organizations to provide respite care under
 4 this Act publicize--the--existence--of,--and--make--available,
 5 application-forms-for-sponsors-seeking-to-establish-a-respite
 6 program.

7 (c) (Blank). The-application--forms--shall--require--the
 8 following--information-and-any-other-information-the-Director
 9 deems-necessary.

10 (1)--Identity-and-qualifications-of-a-sponsor.

11 (2)--Identity-and-qualifications-of-a-provider-and-a
 12 plan-for-the-coordination-of-services.

13 (3)--An-assessment-of-the--community--need,
 14 and--participation--for-respite-services.--The-assessment
 15 shall-include-documentation.

16 (4)--Plans-for-the-coordination-and--arrangement--of
 17 provider-services-in-a-manner-that-meets-client-needs.

18 (5)--A--fiscal--plan,
 19 for-the-utilization-of-existing-reimbursement-and-funding
 20 sources-and-the-development-of-local-financial-support.

21 (6)--Plans--for--publicizing--the--purpose--of--the
 22 project-and-the-services-to-be-provided.

23 (7)--Certification--of-licensure-or-certification-of
 24 any-individual,
 25 agency--or--family--providing--a--service
 subject-to-licensure,
 26 or-certification-under-State-law.

26 (d) (Blank). The-Director-shall-review-and-evaluate-each
 27 application--and--present--each--application--for--review-and
 28 evaluation-by-the-Council-on-Aging-established-under--Section
 29 7--of--the--Illinois--Act--on-the-Aging.--The-Council-and-the
 30 Department-shall-approve-a-number-of-applications-and,
 31 within
 32 the-amounts-appropriated,
 33 award-grants-for-the--operation--of
 34 respite-programs.

33 (e) (Blank). The--application-approved-by-the-Director
 34 and-the-Council-on-Aging-shall-be-the--service--plan--of--the

1 provider.---The--Director--shall--ensure--that--each--service--plan
 2 is--coordinated--with--the--designated--area--agency--provided--for
 3 in--Sections--3.07--and--3.08--of--the--Illinois--Act--on--the--Aging,
 4 the--local--public--health--authority,
 5 and--any--other--public--or
 6 private--service--provider--to--ensure--that--every--effort--will--be
 7 made--to--utilize--existing--funding--sources---and---service
 8 providers--and--to--avoid--unnecessary--duplication--of--services.

8 (f) Nothing in this Act shall be construed to limit,
 9 modify, or otherwise affect the provision of long-term
 10 in-home services under Section 4.02 of the Illinois Act on
 11 the Aging.

12 (Source: P.A. 87-974.)

13 (320 ILCS 10/8) (from Ch. 23, par. 6208)

14 Sec. 8. Funding. Services Respite-projects authorized
 15 under this Act shall be funded only to the extent of
 16 available appropriations for such purposes. The Director may
 17 shall seek and obtain State and federal funds that may be
 18 available to finance respite care grants--awarded under
 19 Section-6-of this Act, and may shall also seek and obtain
 20 other non-state resources for which the State may be
 21 eligible. ~~Implementation-of-projects-under-this-Act-shall-be~~
 22 ~~contingent-upon-the-availability-of-federal-financial~~
 23 ~~participation.---To-the-extent-necessary-for-implementation-of~~
 24 ~~this--Act,~~ The Department may shall seek appropriate waivers
 25 of federal requirements from the U.S. Department of Health
 26 and Human Services.

27 (Source: P.A. 87-974.)

28 (320 ILCS 10/11) (from Ch. 23, par. 6211)

29 Sec. 11. Respite Care Worker Training.

30 (a) A respite care worker shall be an appropriately
 31 trained individual whose duty it is to provide in-home
 32 supervision and assistance to a frail or--abused or

1 functionally disabled ~~or cognitively-impaired-elder~~ adult in
2 order to allow the primary care-giver a break from his or her
3 continuous care-giving responsibilities.

4 (b) The Director may prescribe minimum training
5 guidelines standards for respite care workers to ensure that
6 the special needs of persons receiving services under this
7 Act and their primary caregivers will be met. The Director
8 may designate Alzheimer's disease associations and community
9 agencies to conduct such training. Nothing in this Act
10 should be construed to exempt any individual providing a
11 service subject to licensure or certification under State law
12 from these requirements.

13 (Source: P.A. 87-974.)

14 (320 ILCS 10/12) (from Ch. 23, par. 6212)

15 Sec. 12. Annual Report. The Director shall submit a
16 report each year to the Governor and the General Assembly
17 detailing the progress of the respite care services provided
18 ~~programs--established~~ under this Act. ~~The--report--shall~~
19 ~~include:~~

20 ~~(a)--a-financial-report-for-each-program;~~

21 ~~(b)--a-qualitative-and-quantitative-profile-of--sponsors,~~
22 ~~providers,~~~~care-givers--and--recipients-participating-in-the~~
23 ~~program;~~

24 ~~(c)--a-comparative--assessment--of--the--costs--and~~
25 ~~effectiveness--of--each--service--or--combination-of-services~~
26 ~~provided;~~

27 ~~(d)--an-assessment-of-the-nature-and-extent-of-the-demand~~
28 ~~for-services;-and~~

29 ~~(e)--an-evaluation-of-the-success-of--programs--receiving~~
30 ~~grants-for-services.~~

31 (Source: P.A. 87-974.)

32 (320 ILCS 10/7 rep.)

1 (320 ILCS 10/9 rep.)

2 (320 ILCS 10/10 rep.)

3 Section 91. The Respite Program Act is amended by
4 repealing Sections 7, 9, and 10.

5 Section 99. Effective date. This Act takes effect upon
6 becoming law."